

# The Kansas City Foundation for Pulmonary Fibrosis

## How Close are we to finding a cure for Pulmonary Fibrosis? [Video]

“Drs. Naftali Kaminsky and Danielle Antin Ozerkis, Yale University School of Medicine, gives a glimpse into their research and medical therapy development progress in finding a cure for pulmonary fibrosis. The committed research team at Yale has studied potential cures for years and now plans to fast-track the cumulative knowledge into important next steps.” Bill Vick, PF Warriors.

Video Link: <https://www.youtube.com/watch?v=eBIBZBRzHQM>

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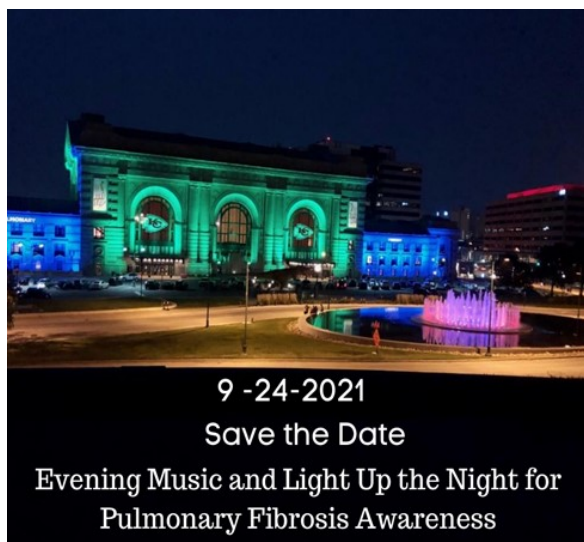
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Sep 19, 2020, KCFPF lit up Union Station for PF Awareness (photo by Matt Shanahan)

## 4th Annual Light up the Night for Pulmonary Fibrosis



*Sep 19, 2020, KCFPF lit up Union Station for PF Awareness (photo by Kay Trieb)*

### Program

- Friday, September 24th, 2021, Grand Plaza Hall, Union Station
- KCFPF Display Table for Public viewing: 12:30 – 2:30 pm
- Starts at 6:30 and Ends at 10 pm.
- Presentations at 7 pm.
- Billy Ebeling and The Late for Dinner Band at 7:30 pm
- View Union Station Lit Up 8:20 pm
- Silent Auction starts at 6:30 pm

### Tickets

Tickets will be available to purchase on August 1, 2021.

The cost is \$100 per individual.

The cost for persons with PF, family members, care partners, transplant recipients, or those who have lost a loved one to attend is \$75 per ticket.

For more information go to KCFPF [website](#).



[Billy Ebeling and The Late for Dinner Band](#)

### Virtual 2021 PFF Summit

The 2021 PFF Summit dates are November 8 - 13.

Click here for the [program](#).

KCFPF will provide grants to persons with PF, family members, care partners, transplant recipients, or those who have lost a loved one to attend the virtual summit.

The grant will cover the registration fee. A family is limited to purchasing two packages. You will only need one package if multiple persons are attending the conference together (e.g., a Person with PF and their care partner watching at home). Persons with PF and transplant recipients must reside in Kansas or Missouri.

To request a grant, click [here](#).

2021 PFF Summit registration will be from June 14th through November 5th at 3 pm.

## Fight for Air Climb by Kevin Olson



*Bert, Jamie, Janell, Kevin (photo by Dana Olson)*

On June 13, 2021, Bert Maidment and I completed the American Lung Association [Fight for Air Climb](#). It was a fun and rewarding event. We climbed 1400 stairs. Bert honored his two sisters and brother-in-law, who passed away from lung cancer on both climbs. Kevin and Dana honored his lung donor, his mom, who passed away with COPD, and her father, who passed away with IPF.

It was the second time Bert did the climb. In 2020, Bert completed a rise of 42 flights of stairs which was 902 stairs. He used his [Inogen G5](#) portable oxygen Concentrator during his climb. Using oxygen, he caught the attention of TV station Channel 9 ABC news. They [interviewed](#) Bert. Bert brought awareness to his IPF and lung cancer.

Since the 2020 climb, Bert's need for oxygen increased. He required 8 Liters of O<sub>2</sub> and used E-size Oxygen tanks for training. However, Bert believed he could still use his Inogen G5 POC for the 2021 Fight for Air event. He planned to climb a short distance, then rest and repeat.

Bert had planned for a second POC for backup, but his Durable Medical Equipment supplier backed out of supplying him a second concentrator. Jamie Ludwig and Janell Reichuber came forward to help him. Jamie and Janell contacted the PURAIR Oxygen Supply company. CEO Michael Carr volunteered to sponsor Bert and supplied him with a liquid oxygen tank containing 24 hrs worth of O<sub>2</sub> and two canis-

ters.

Bert required even more oxygen than the 8 liters when he trained. He had to use 15 liters of O<sub>2</sub>, which the liquid O<sub>2</sub> canisters. He would not have completed the climb without having the liquid oxygen.

In support of Bert, Kevin, and Dana Olson, Jamie and Janell registered for the climb.

Being a double lung transplant recipient, Fox 4 and CBS Channel 5 interviewed Kevin. He was on the Fox 4 morning show opening the American Lung Association Fight for Air Climb. The interview discussed his IPF, his lung transplant, and the KC Foundation for PF. On the Fox 4 evening news, they had a different report using some of his comments. On CBS, Channel 5 had information on the Fight for Air Climb using some of his words.

After walking the course, Janell and Jamie went back to the starting line and ran the course. You can see pictures and videos of the Fight for Air Climb [here](#).



*2021 06 13 Bert and Kevin Finish line (photo by Dana Olson)*

## Asthma and Pulmonary Fibrosis

Charlene Marshall, a columnist for Pulmonary Fibrosis News, wrote: "Understanding the Relationship Between Asthma and Pulmonary Fibrosis." She writes about initially diagnosed with asthma, then IPF. Now her pulmonologist believes she has IPF with asthma. IPF is associated with several comorbidities, including pulmonary

hypertension, lung cancer, and gastroesophageal reflux disease (GERD). Charlene investigates IPF and Asthma to see if there are any connections.

Read the full article here: <https://pulmonaryfibrosisnews.com/2021/06/10/asthma-pulmonary-fibrosis-what-is-relationship/>



*Image Licensed under Creative Commons*

## How to Make the Most of Summer Despite Pulmonary Fibrosis

- Plan ahead for time outdoors
- Embrace a new hobby

These are the two main recommendations from Charlene Marshall on how to enjoy the summer months on supplemental oxygen.

Read the full article here: <https://pulmonaryfibrosisnews.com/2021/06/17/summer-tips-supplemental-oxygen-ipf/>



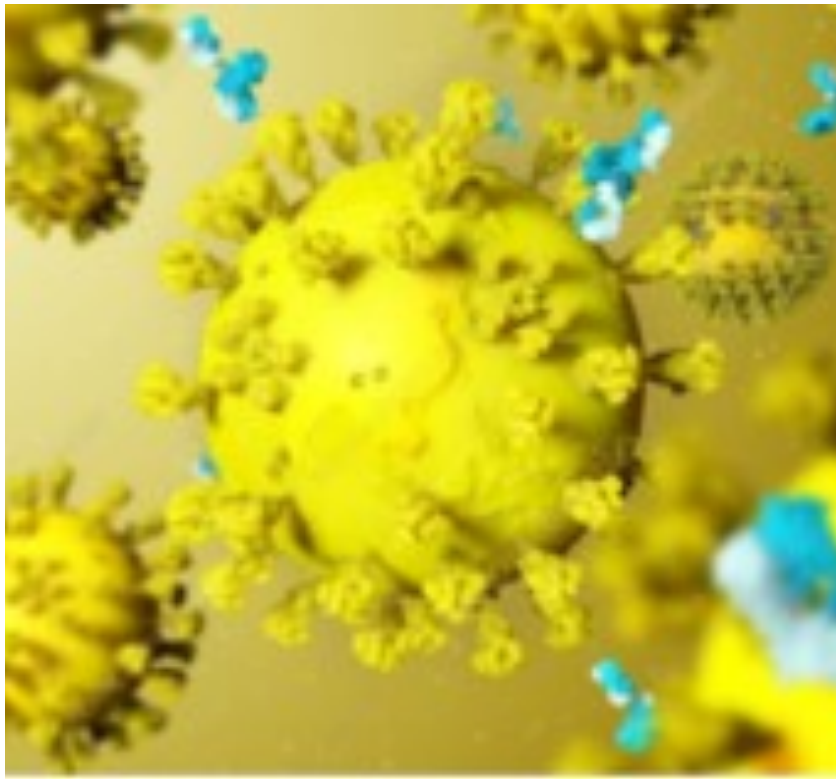


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## Esbriet Slows IPF Progression Regardless of Self-Reactive Antibodies

Margarida Maia, Pulmonary Fibrosis writer, examines how Esbriet affects IPF progression in reference to self-reactive antibodies.

According to a study published in the *BMC Pulmonary Medicine* journal, "Esbriet (pirfenidone) appears to slow the progression of idiopathic pulmonary fibrosis (IPF) regardless of the presence of autoantibodies, which might mean the therapy can work even when IPF is linked to an autoimmune disease."

Read the full article here: <https://pulmonaryfibrosisnews.com/2021/06/11/esbriet-may-slow-ipf-regardless-of-autoantibody-status/>

## Covid Vaccine

Labcorp offers test to check for antibodies to COVID-19. More info go here:

[https://www.labcorp.com/coronavirus-disease-covid-19/individuals/antibody-test?fbclid=IwAR34INu51ZYpCZP3gMePGNYp-CYsiG-Ma\\_7EQ\\_VSx\\_mNhR6tMYzL9ICI-WSs](https://www.labcorp.com/coronavirus-disease-covid-19/individuals/antibody-test?fbclid=IwAR34INu51ZYpCZP3gMePGNYp-CYsiG-Ma_7EQ_VSx_mNhR6tMYzL9ICI-WSs)

## Pulmonary Paper

"The Pulmonary Paper was founded and first published by Celeste Belyea in 1988 – before the Internet and portable oxygen concentrators were available – as a means to connect, educate and support people who were dealing with chronic respiratory problems." - Pulmonary Paper.

Pulmonary Paper publishes a quarterly newsletter. It is free to view online. Every summer newsletter compares Portable Oxygen Concentrators. Great source of information.

See below for link to Pulmonary Papers 2021 Summer Newsletter.

<https://www.pulmonarypaper.org/newsletters/>

You can receive the newsletters via email. Send a request to

[online@pulmonarypaper.org](mailto:online@pulmonarypaper.org)

*"The rate of progression of fibrosis in chronic ILD varies a great deal from one person to another." - Lung & You*

## Pulmonary Fibrosis Progression



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The Lung and You website has the article "What Should I Expect if ILD Progresses?".

The articles talks about these topics.

- About Breathlessness
- What Are Exacerbations?
- What Can Happen During an Exacerbation?
- Who Gets Exacerbations?
- Provides a link to Learn more about progression and why early detection is important.

For complete article click [here](#).

Responsum for PF website has this article plus a video "An Introduction to Pulmonary Fibrosis Progression". Topics are below.

- Understanding PF progression
- Monitoring PF progression
- PF progression is different for everyone

For complete article click [here](#).

### Vitamin D and PF

Dandan Ma and Lipan Peng on Sep 1, 2019, published "Vitamin D and pulmonary fibrosis: a review of molecular mechanisms"

Warning: This is a technical article but it has some areas of interest to person with PF. That information can be found in the following sections:

- Abstract
- Introduction
- The distinct stages of pulmonary fibrosis and vitamin D
- Discussion

For complete article click [here](#).

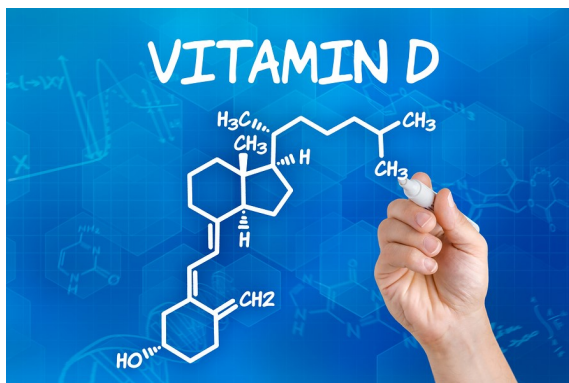


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*The Kansas City Foundation for Pulmonary Fibrosis (KCFPF) is a nonprofit organization dedicated to improving the lives of patients with pulmonary fibrosis and other rare lung diseases through education, technology, and research.*

## Volunteers Wanted!

The Foundation would like volunteers for these committees.

**Fundraiser Committee:** Subcommittee will be to make recommendations to the Board on the annual fundraiser. The subcommittee will also explore additional fundraising opportunities outside of an annual event.

**Patient Initiative Committee:** The purpose of the Foundation Patient Initiative Committee is to be good listeners and observers of the Pulmonary Fibrosis Community and identify, research and propose opportunities the Foundation can financially support to make life easier.

**Media Committee (Website, FB, News, Newsletter):** The main role of the Media Subcommittee will be to spread awareness, distribute educational and grant information, advertise events which are developed by the other subcommittees. The primary focus will be on website and Facebook updates, but other media will be used dependent upon the target audience.

Visit Here to sign up: <https://www.kcpulmonaryfibrosis.org/want-to-help>

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